Neutral Citation Number: [2024] EWCOP 62 (T3)

Case No: 12866050

IN THE COURT OF PROTECTION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 30/10/2024

Before :

Mrs Justice Theis DBE
Vice President of the Court of Protection

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Between :

NHS North West London Integrated Care Board **Applicant**
- and -
AB (by her litigation friend the Official Solicitor)
- and -
The Royal Hospital for Neuro-disability
- and -
CD
- and -
PB **Respondents**

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Susanna Rickard (instructed by **Capsticks**) for the **Applicant**
Fiona Paterson KC (instructed by **the Official Solicitor**) for the **First Respondent**
Katie Scott (instructed by **Bevan Brittan LLP)** for the **Second Respondent**
CD, the **Third Respondent and PB,** the **Second Respondent, attended in person and were not represented**

Hearing date: 16 October 2024
Judgment: 30 October 2024

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Approved Judgment

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This judgment was delivered in public but a transparency order is in force dated 30 October 2024. This judgment is published on condition that (irrespective of what is contained in the judgment) in any published version of the judgment the anonymity of AB must be strictly preserved. All persons, including representatives of the media and legal bloggers, must ensure that this condition is strictly complied with. Failure to do so may be a contempt of court.

Mrs Justice Theis

Introduction

1. Until March 2015 AB was a lively, energetic and much loved mother to three children, with an wide circle of family and close friends. Tragically, on 30 March 2015 AB, age 50, suffered a subarachnoid haemorrhage, secondary to a right cerebral artery aneurysm during an exercise class. She was intubated and ventilated at St Mary's Hospital and then transferred to the intensive care unit at Charing Cross Hospital where she underwent neurosurgery to stem the aneurysmal bleeding. In July 2015 she was transferred to the Brain Injury Service at the Royal Hospital for Neuro-Disability (the RHN) for formal assessments of awareness, disability management and discharge planning. In December 2015 she was discharged into the Specialist Nursing Home within the RHN, where she has remained for nearly nine years.

2. Since the injury AB has remained in a prolonged disorder of consciousness (PDOC), and is diagnosed as being in the lower end of a minimally conscious state (MCS minus). She is entirely dependent on others for all aspects of her care and receives clinically assisted nutrition and hydration (CANH) through a percutaneous endoscopic gastrostomy (PEG) tube. Since 2015 AB has had little or no conscious awareness of herself or her environment.

3. The court is concerned with an application by the North West London Integrated Care Board (ICB) dated 10 May 2024 for the court to determine whether it is in AB's best interests for continuation of CANH. The clinical view of the RHN is that it is not in AB's best interests for CANH to be continued. That view is shared by some of AB's family but not all of them, with the result this application is brought before the court to determine. AB is represented by her litigation friend, the Official Solicitor. The other parties to the application are AB's sister, CD, and her eldest son, PB.

4. The hearing took place on the 16 October 2024 and was attended by members of AB's family and friends, many of whom were present in court. AB's two aunts, who live abroad, attended remotely. In addition to the extensive court bundle I heard oral evidence from Dr D, Consultant in Neurorehabilitation at the RHN. The family were able to ask him questions through Ms Paterson KC for the Official Solicitor.

5. I visited AB on 18 October 2024 at the RHN together with the Official Solicitor's representative. A note of that visit has been circulated to the parties.

6. Before I turn to set out the background to the case I would like to pay tribute to AB's family and friends who attended the hearing. They listened with great care to the oral evidence, sought further information through questions by Ms Paterson and have liaised with the other parties in the lead up to and during this hearing. The court recognises how difficult this hearing must have been for them and the sadness they all feel for the situation AB is in with the loss that represents for each of them. Their continued involvement in discussions regarding AB's care over so many years and these proceedings speaks for the strength of their loyalty, affection and love for AB.

7. I would also like to recognise those who care for AB on a day to day basis. During my visit to the RHN to see AB it was very clear that her day to day care needs have been met to the highest standard by a dedicated clinical team. The ward matron has worked at the RHN throughout the period AB has been there and many of the other nurses on

the ward who care for AB had been there for a number of years. They all spoke about AB with enormous care and appeared very attuned to AB's day to day care needs.

8. In *North West London Clinical Commissioning Group v GU* [2021] EWCOP 59 Hayden J, Vice President of the Court of Protection, expressed concern at the inordinate and inexcusable delay by the RHN in that case in determining whether continuing to receive CANH was in GU's best interests. Hayden J made clear that in accordance with his guidance (Serious Medical Treatment [2020] EWCOP 2)

   [103] '*…where the treating hospital is, for whatever reason, unable to bring an application to the court itself, it should recognise a clear and compelling duty to take timely and effective measures to bring the issue to the attention of the NHS commissioning body with overall responsibility for the patient.'* and

   [105] *'Regular, sensitive consideration of P's ongoing needs, across the spectrum, is required and a recognition that treatment which may have enhanced the patient's quality of life or provided some relief from pain may gradually or indeed suddenly reach a pivoting point where it becomes futile, burdensome and inconsistent with human dignity. The obligation is to be vigilant to such an alteration in the balance'.*

9. As set out in more detail below, as a result of the *GU* case the RHN undertook a wholesale systemic review of their practices and procedures. In the detailed statements from Dr Luttrell, Medical Director of the RHN, he states the RHN *'has fully engaged with the criticisms raised in the GU case and is fully committed to dealing with them'.* Dr Luttrell recognises that following AB's admission to the RHN '*there was no formal best interest review as to whether CANH should be continued'.*

10. For AB a formal best interest review was not started until early 2023, seven and a half years after her admission to the RHN. The RHN realistically recognises there has been delay to decisions being made, including for AB and her family. The reasons for that was a systemic failure in the RHN to have the relevant framework in place for making these best interest decisions in a timely way. Prior to the recent changes there was simply a vacuum within the RHN, with no system for best interest decisions to be made.

11. I fully associate myself with the observations made by Hayden J in *GU* about the impact of the delay in making best interest decisions on the person who is the subject of a best interest decision and the wider family. I agree with the Official Solicitor that there were inordinate and inexcusable delays that took place in this case in assessing and making any best interest decision regarding AB over many years in circumstances where AB's situation had not changed and if AB did experience anything it was likely to be distress.

12. Following their review in 2022 the legal framework and the wider landscape in the RHN are now pellucidly clear, providing a requirement for regular structured reviews of a person who is in PDOC, with an intense focus on their individual ongoing needs and timely best interest decisions being made. At each stage those decisions need to undertake the balance whether treatment which may have enhanced the patient's quality of life or provided some relief from pain may '*gradually or indeed suddenly reach a pivoting point where it becomes futile, burdensome and inconsistent with human dignity. The obligation is to be vigilant to such an alteration in the balance*' (per Hayden J in *GU [105]).* Whilst not detracting from the excellent care afforded to AB it is unacceptable that decision making structure did not happen in AB's case for

many years due to the essential framework for that to be done simply not being present in the RHN.

13. The framework now outlined in Dr Luttrell’s statements is a welcome and long overdue development that will ensure the delays in best interest decisions being made for those in PDOC will not occur in the future in the way they did for AB and her family. This includes, importantly, where there is no agreement or the decision is finely balanced for an application to be made to the Court of Protection to be determined.

Relevant background

14. Following AB’s haemorrhage in 2015, secondary to a right middle cerebral artery aneurysm, the bleeding aneurysm was successfully treated through being coiled by neurosurgery in an acute hospital. AB was referred to the RHN by her acute hospital as being in a PDOC for further formal assessments. AB was initially admitted to the Brain Injury Service (BIS) at the RHN for more formal assessments of awareness, disability management, and discharge planning. Five months later in December 2015 AB was discharged to the Specialist Nursing Home (SNH) at the RHN where she has resided for the last eight years. AB’s stay at the RHN SNH is commissioned by the ICB, funded through CHC (Continuing Health Care) funding and is reviewed annually.

15. AB’s other medical background includes primary hyperparathyroidism, secondary to a parathyroid adenoma. This leads to the removal of calcium from the bones and increased blood calcium levels. AB also suffers from an auto immune skin condition, hyperthyroidism and an element of Chronic Obstructive Pulmonary Disease. These conditions are each managed by appropriate medications.

16. Between July and December 2015 AB had assessments to establish a formal diagnosis of being in a Minimally Conscious State (MCS) as a result of her brain injury. AB sits in the lower category of the minimally conscious spectrum (MCS minus). This was in keeping with the national guidelines available at the time (Prolonged disorders of consciousness following onset brain injury: National clinical guidelines 2013) published by the Royal College of Physicians (RCP). This has since been updated to the 2020 RCP PDOC Guidelines.

17. This diagnosis meant AB has only very minimal and inconsistent awareness of herself or the environment around her. As the GP who has had responsibility for AB’s care since 2018 stated this diagnosis *‘made in 2015 remains unchanged following her most recent neurological status examination in November 2023’.* Put simply, there had been no change in AB’s diagnosis over eight years and her condition is highly unlikely to change.

18. Over the last three years AB has been treated for about twenty infections including Covid-19, skin infections and urinary tract infections. AB was last admitted to an acute hospital in 2020 and since then has had in place a Treatment Escalation Plan (TEP) which meant she is not for transfer to the acute hospital.

19. AB has been visited by members of her family over her extended period at the RHN, including her children, her siblings, niece and other family members and friends.

Medical evidence

20. Since her admission to the RHN AB has been in receipt of 24 hour care and she cannot undertake any activities of daily living or provide any aspect of her care for herself.

21. That high level of care is explained in the statement from her GP as follows:
    (1) Administration of medication via the PEG as well as application to the skin or scalp if indicated.
    (2) Fluid balance chart when AB is unwell and requires close observation.
    (3) Administration of CANH regularly throughout the day. More hydration can be indicated when weather is warmer due to increased risk of dehydration.
    (4) Daily PEG site care to prevent infection.
    (5) Regular skin and pressure area care to maintain skin integrity and prevent formation of any ulcers. This includes regular repositioning, moving and handling.
    (6) Physiotherapy and occupational therapy involvement when indicated (it is not something that is regularly provided in long term care).
    (7) Personal care is provided on a daily basis with regular intervention from care staff to help with AB's needs.
    (8) AB's tracheostomy tube is changed every 28 days and she requires regular suctioning four times a day from her tracheostomy on a 12 hour shift. AB presents with increased respiratory secretions that can manifest with episodes of desaturations hence why regular suctioning is warranted.
    (9) AB remains dependent on two people for moving and handling. For bed mobility, she needs a slide sheet and for transfers, she uses a sling and hoist to transfer to the wheelchair and vice versa.
    (10) AB is doubly incontinent and uses continence pads and in addition she has an ongoing long term sacral cleft skin issue. It has been managed with use of a medical grade foam mattress, barrier cream, foam dressing and personalised turning schedule (3 to 4 hourly).
    (11) AB is known to experience high tone and contractures. AB's physical presentation is currently being managed through splinting and a 24 hour postural management programme. It has been identified that her head is not always well supported in her current seating system, however, AB can actively move her head so no changes to improve this can be made.
    (12) AB is under continual surveillance for her hyperparathyroidism that leads to hypercalcaemia. This requires regular blood tests and monitoring.
    (13) AB's clinical team work closely with the dietitians to ensure her fluid intake/balance is optimised to ensure her calcium levels remain normal for as long as possible prior to administration of denosumab.
    (14) During personal care and whilst undergoing moving and handling, AB is known to grimace and display pain behaviours, AB is nursed using intentional rounding; this is a system of care in which nurses and care staff periodically check patients to ensure their needs are met. This involves checking their positioning, any pain behaviours, personal needs (including continence needs) and that any personal items are accessible.

22. AB's level of awareness during the assessments has been described in different ways but all remain consistent that AB's responses are mainly reflexive. Her GP describes it as follows *'she moves away from noise as a reflex but not in a meaningful manner. She is able to inconsistently localise when name called only – this means that she looks towards the person calling her name. [AB] is able to visually track people with some reflexive smiling and frowning. Although these behaviours are usually associated with emotion (pleasure or pain), for [AB] these responses appear*

spontaneous and are not interpreted to be meaningful. There are some infrequent occasions when she has been observed to smile at staff. However this is likely to represent chance association with a stimulus, rather than cause and effect'.

23. Her GP describes that AB does appear to be in discomfort at times, usually associated with personal care, transfers between bed and chair and repositioning. Her daily routine consists of personal care in the morning following which she is usually transferred into the chair. She is repositioned every four hours, transferred back into bed later in the day and continues to be repositioned every four hours. Although AB is prescribed pain relief AB *'grimaces on movement and withdraws her limbs towards her body. Due to the severity of brain injury and PDOC diagnosis, it is not possible to establish whether she is consciously experiencing pain on these occasions…'.*

24. In his detailed written evidence Dr D outlines the PDOC assessments that have been undertaken in accordance with the 2020 RCP PDOC Guidelines. He outlines recent difficulties AB has had including in managing AB's posture in her wheelchair, the splinting regimen in her upper limbs as applying her splints on a daily basis seems to cause more distress and involuntary resistive movements. The clinical team report it is getting more difficult to care for AB as she has generalised dystonia affecting all four limbs and her neck, with some being very stiff to move or tight to open and her palmar creases were noted to be *'moist, excoriated and malodorous'* despite attempts at good personal care and hygiene.

25. In his statement Dr D described AB as follows: *'[AB] has no reliable means of communication. Her facial movements appear to be dystonic (involuntary rotational and sideways movements of her face, especially the lower half, with opening of her mouth widely, protrusion of the tongue, and 'grimacing' movements). None of these are consistent, can occur with and without stimulation (arousal), and generally increase after a noise (most commonly a greeting or command). This is her baseline. These eloquent movements do not seem to increase in response to a focused stimulus like a loud clap, a bright light, or a verbal command. These may or may not be associated with eye opening. There is no co-occurrence of any limb movement. In my opinion, these are not communication behaviours, and do not show an intent to communicate or follow a verbal or implied command. They are resting behaviours, due to widespread deep brain grey matter disease, sustained at the onset of her brain injury in 2015 and which persist to date.'*

26. Following the PDOC assessments in 2015 that concluded AB was in MCS minus there were periods of review in January 2017, July/August 2018, October/November 2019, December 2020 to February 2021, January 2022, November 2022 and November 2023. Dr D sets out his conclusions from all these assessments from December 2015 to November 2023 as follows:
a. They are in line with recommendations in the PDOC Guidelines.
b. They have been completed by competent PDOC observers and assessors.
c. They have consistently put her diagnosis at the lower end of the consciousness spectrum at MCS-
d. None of these behaviours have become progressively 'better', in the sense they have not been built upon to increase her number of communication behaviours, nor have they resulted in any command following which would be indicative of MCS 'plus' type behaviours. None of them consistently convey a positive or negative experience of either pleasure or distress.
e. The 'smiling' reported consistently, in the absence of any other behaviours that would indicate pleasure (or, as a corollary, a capacity for suffering) are likely to be

> *her evolving facial movements of dystonia, which are very evident on examination in 2024. These are involuntary movements without any meaning extracted from stimuli applied, or any communication intent behind their façade.*

27. In June 2024 Dr D undertook updated assessments which showed no change. He concluded this is a permanent state and there is no prospect of improvement in her neurological status, but one of deterioration. Dr D considers AB's life expectancy with continued treatment is *'likely to be less than 3-4 years'* subject to any infection. Her life expectancy would be 1-3 weeks should CANH cease. Dr D considers her current TEP, that she should not be transferred off site unless there is a clear benefit in doing so, is in her interests, as is the DNACPR (Do Not Attempt Cardio-Pulmonary Resuscitation). Dr D describes AB as being in a state of managed comfort if the restlessness and dystonia are discounted. Dr D does not consider any further investigations, treatments or assessments are required.

28. Dr D concludes that continuing CANH is not in her best interests as follows:
    'I have no doubts considering all aspects of her diagnosis, prognosis, and her patent life interests that she can now no longer enjoy or hope to regain, to even a semblance of the vibrant woman she was, continuing CANH is not in her best interests. Further, I would also recommend that other investigations like blood tests, treatment of her raised serum calcium, detecting and treatment of all infections, should not be treated aggressively.
    Timely, expert, and proportionate treatment would indicate a Palliative Care Plan underscored by realistic treatments on offer, and good symptomatic management of the end of life. The necessary nursing care episodes and treatments she currently gets are increasingly intrusive, difficult and burdensome. They are potentially distressing, and are delivered to an increasingly frail woman with no clinical benefit or hope of improvement to a level she would have accepted. They are thus futile at every level in returning her to the person of [AB], an identity she treasured, and which has now permanently departed.'

29. In his oral evidence Dr D described AB's continued survival is attributable to the brain stem, which although injured is very resilient and continues to function maintaining AB's breathing, heart, temperature regulation and the production of hormones however, as Dr D stated, the rest of her brain *'the loving, planning...brain, has not been there since 2015'.* Dr D was satisfied that AB had not suffered from a reversable form of hydrocephalus and no further investigations were required. Dr D was as certain as he could be that AB's recovery from her injuries had reached its full potential and she would remain in her current low level of awareness. In his oral evidence Dr D said that the assessments had shown that AB had exhibited half or one conscious behaviour and her levels of awareness had barely moved in nearly nine years. Dr D did not consider there was any emotional content to AB's smiles and the tracking with her eyes was due to her retaining her vision rather than any discerning behaviour. The smiles were more likely to be reflexive movements within her facial muscles than a response borne out of pleasure and/or affection. If AB did experience pain Dr D did not consider she experienced pleasure or comfort due to the extent and severity of her brain damage. He outlined in his oral evidence what he considered to be the deteriorating clinical picture as AB required more care interventions such as suctioning and managing her muscle tone and dystonia and if she did experience anything it was likely to be negative but Dr D remained uncertain about this.

30. Dr D's evidence was that AB's life expectancy if CANH continued was four years but he considered she was at increasing risk of infections and considered AB would probably die from an infection which would develop into organ failure resulting from sepsis, which could happen quite quickly.

31. Dr D's oral evidence about the palliative care plan was that he considered AB would die in seven to ten days of CANH being withdrawn, as she did not have the reserve to survive much longer due to her wider health needs. Overall he considered AB would experience less distress than she currently does as many of the current interventions would be stopped and it is unlikely that someone with AB's low levels of awareness will experience hunger and thirst.

32. Dr Nair, Consultant in Rehabilitation Medicine, was instructed to provide a second opinion in accordance with the 2020 RCP PDOC Guidelines. In his initial report he raised the issue as to whether obstructive hydrocephalus, as a reversible cause or treatable condition, had been fully excluded. Although he recognised the difficulties there would be in undertaking any further investigations or treating AB it was not his area of expertise. A 2018 scan was obtained which Dr Nair reviewed but maintained his recommendation that a report from a neurosurgeon was obtained to confirm that hydrocephalus was not contributing to AB's presentation. A further opinion was sought from Mr Mitchell, Consultant Neurosurgeon. He confirmed if the hydrocephalus was treated it would not change or improve AB's position. Dr Nair accepted that opinion and concluded that it was not in AB's best interests to undergo any further investigation or treatment and that withdrawal of CANH was in her best interests.

AB's wishes and feelings

33. Since January 2023 structured discussions have been taking place with AB's family and friends. They have described AB as being active throughout her life, as an extraordinarily great mother who loved her boys, the matriarch of the family who gave advice, tried to bring people back together, was outgoing, loved being around people and was social. AB has been reported as being "*funny, bold, loved being around people, very strong, strong work ethic, loving, caring and [with an] infectious laugh.*", she was "*family-orientated, funny [a] happy person, worked every day, active…" and "funny, cheeky, strong, independent, amazing*."

34. In the discussions with the family the majority of them made it clear that being in her current condition is not what AB would have wanted, as one of her children said she "*would not want to sit in a chair for the rest of her life, I know that*", adding later "*If she had the decision to choose a different way out, it is not the way of life and not what she would have wanted*." Another said "*being the life and soul of the party, I feel like she would not want to be seen like this and in bed all the time, she'd want to be let go*." No one has described AB as holding any particular religious beliefs but she understood the importance of it and its place in her life. AB's brother stated "*let her go now instead of prolonging it. She can't do anything, [she was an] active person, a people person*". He believed that discontinuation of CANH is "*what is best for her*."

35. However that was not the view of them all, PB expressing the view that AB *"would want it to be natural*", when she is *"ready"* although agreeing AB's current quality of life was not acceptable "*at all for anybody*" but felt AB would want CANH to continue.

Legal framework

36. There is agreement between the represented parties as to the relevant legal principles.

37. Where a person lacks capacity to decide for themselves, any decision must be made in their best interests (s1(5) MCA 2005).

38. In the context of decisions as to whether to withdraw life-sustaining treatment, the Supreme Court in *Aintree University Hospital NHS Foundation Trust v James* [2013] UKSC 67 (at §22) identified the ambit of the court's inquiry as follows:

> *"… the focus is on whether it is in the patient's best interests* *<u>to give the treatment,</u>* *rather than on whether it is in his best interests to withhold or withdraw it. If the treatment is not in his best interests, the court will not be able to give its consent on his behalf and it will follow that it will be lawful to withhold or withdraw it. Indeed, it will follow that it will not be lawful to give it. It also follows that (provided of course that they have acted reasonably and without negligence) the clinical team will not be in breach of any duty towards the patient if they withhold or withdraw it." [emphasis added]*

39. CANH is recognised as a medical treatment amenable to such a determination (per Lady Black, with whom the other members of the court agreed, in *An NHS Trust v Y* [2018] UKSC 46).

40. The starting point for any best interest analysis is a strong presumption that it is in a person's best interests to stay alive, considering their rights under Article 2 (the right to life), Article 3 (protection from inhuman or degrading treatment) and Article 8 (the right to respect for private and family life) of the European Convention on Human Rights ("ECHR").

41. In *W v M* [2011] EWHC 2443 (Fam), Baker J (as he then was) expressed that this presumption can be *"simply stated but [is] of the most profound importance"* and "*carries very great weight in any balancing exercise*" (§222).

42. The strong presumption of maintaining life, however, can be displaced by evidence that it would be contrary to a person's best interests to continue receiving life-sustaining treatment. Having enunciated this point, Lady Hale in *Aintree* continued that:

> "36. *The courts have been most reluctant to lay down general principles which might guide the decision. Every patient, and every case, is different and must be decided on its own facts. As Hedley J wisely put it at first instance in Portsmouth Hospitals NHS Trust v Wyatt [2005] 1 FLR 21, "The infinite variety of the human condition never ceases to surprise and it is that fact that defeats any attempt to be more precise in a definition of best interests" (para 23). There are cases, such as Bland, where there is no balancing exercise to be conducted. There are cases, where death is in any event imminent, where the factors weighing in the balance will be different from those who life may continue for some time."*

43. Where a decision relates to life-sustaining treatment, the person making the decision must not *"be motivated by a desire to bring about his death"* (s4(5) MCA 2005).

44. When determining what is in a person's best interests, consideration must be given to all relevant circumstances, to the person's past and present wishes and feelings, to the beliefs and values that would be likely to influence their decision if they had capacity, and to the other factors that they would be likely to consider if they were able to do so (s4(6) MCA 2005).

45. Account must be taken of the views of anyone engaged in caring for the person or interested in their welfare (s4(7) MCA 2005).

46. The MCA 2005 Code of Practice ("the Code"), issued pursuant to s.42 MCA 2005, provides guidance in respect of best interests decision-making around life-sustaining treatment. This includes that:

> *"5.31 All reasonable steps which are in the person's best interests should be taken to prolong their life. There will be a limited number of cases where treatment is futile, overly burdensome to the patient or where there is no prospect of recovery. In circumstances such as these, it may be that an assessment of best interests leads to the conclusion that it would be in the best interests of the patient to withdraw or withhold life-sustaining treatment, even if this may result in the person's death. The decision-maker must make a decision based on the best interests of the person who lacks capacity. They must not be motivated by a desire to bring about the person's death for whatever reason, even if this is from a sense of compassion. Healthcare and social care staff should also refer to relevant professional guidance when making decisions regarding life-sustaining treatment."*
>
> *"5.32. As with all decisions, before deciding to withdraw or withhold life-sustaining treatment, the decision-maker must consider the range of treatment options available to work out what would be in the person's best interests. All the factors in the best interests checklist should be considered, and in particular, the decision-maker should consider any statements that the person has previously made about their wishes and feelings about life-sustaining treatment."*
>
> *"5.33 Importantly, section 4(5) cannot be interpreted to mean that doctors are under an obligation to provide, or to continue to provide, life-sustaining treatment where that treatment is not in the best interests of the person, even where the person's death is foreseen. Doctors must apply the best interests' checklist and use their professionals skills to decide whether life-sustaining treatment is in the person's best interests. If the doctor's assessment is disputed, and there is no other way of resolving the dispute, ultimately the Court of Protection may be asked to decide what is in the person's best interests."*
>
> *"5.38. In setting out the requirements for working out a person's 'best interests', section 4 of the MCA 2005 puts the person who lacks capacity at the centre of the decision to be made. Even if they cannot make the decision, their wishes and feelings, beliefs and values should be taken fully into account – whether expressed in the past or now. But their wishes and feelings, beliefs and values will not necessarily be the deciding factor in working out their best interests…"*
>
> *"5.41 The person may have held strong views in the past which could have a bearing on the decision now to be made. All reasonable efforts must be made to find out whether the person has expressed views in the past that will shape the decision to be made. This could have been through verbal communication, writing, behaviour or habits, or recorded in any other way (for example, home videos or audiotapes)."*

47. The holistic nature of the best interests analysis was expressed by Lady Hale in *Aintree* as follows [39]:

> "*The most that can be said, therefore, is that in considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be".*

48. At [45] she added:

> *"The purpose of the best interests test is to consider matters from the patient's point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want. Nor will it always be possible to ascertain what an incapable patient's wishes are. .... But insofar as it is possible to ascertain the patient's wishes and feelings, his beliefs and values or the things which were important to him, it is those which should be taken into account because they are a component in making the choice which is right for him as an individual human being".*

49. A number of cases have sought to provide a helpful non-exhaustive list of issues requiring determination in an application of this kind, for example Cobb J in *PL (by her litigation friend, SL) v Sutton CCG & Anor* [2017] EWCOP 22 at [9].

Submissions

50. The court received written submissions from the RHN and on behalf of the Official Solicitor. Although given the opportunity if they wished to do so the family did not send in anything further in writing. The ICB provided the court with a case summary and legal framework, as well as a position statement drawing the court's attention to matters of detail in the written evidence which supplemented the more concise case summary, but did not provide written submissions addressing AB's best interests.

51. Ms Rickard on behalf of the ICB submits that whilst acknowledging the importance of the presumption to preserve life in this case the evidence demonstrates the considerable burdens that arise from AB's condition and the continuing treatment she requires. There is no clear evidence of AB's wishes and feelings regarding the situation she is now in, however the majority of her family and friends who have been consulted believe that to cease providing CANH would be in her best interests. Her son, PB, has been less clear about this preferring things to take place *'naturally'* rather than through the withdrawal of CANH. .

52. Ms Scott, on behalf of the RHN, submits that the medical evidence is clear that AB is in PDOC and at the lower end of conscious awareness, diagnosed as MCS minus which the RCP's PDOC Guidance describes as a *'state of severely altered consciousness in which minimal but clearly discernible behavioural evidence of self or environmental awareness is demonstrated'* [Table 1.2].

53. The multiple assessments undertaken of AB by expert PDOC practitioners designed to assess her level of awareness have concluded AB has no ability to communicate, no functional movement and no ability to follow a command. The highest behaviours seen during the assessment are a smile, inconsistently making eye contact and tracking an object. Dr D's evidence was that the smile he saw was not one with emotional content and did not consider AB's behaviours were inconsistent with her being in a vegetative state.

54. Ms Scott submits the contrast between AB before and after the injury is stark. AB is not the same person that she was prior to the injury, when she was described as being active and energetic. She is now wholly reliant on others for every aspect of her care and her complex and extensive care regime that keeps her alive involves multiple care interventions regularly during the day and night which she has no ability to resist, with the possibility that she has some kind of negative painful experience from some of those interventions.

55. Ms Scott submits the presumption of life is outweighed by the burdens of AB's conditions, including that she has little, if any, awareness of herself or her environment, and her numerous treatments and interventions. There is the possibility that she may experience pain but it is unlikely that she experiences pleasure. There is no prospect of AB recovering and the evidence points towards a continual and steady deterioration in her condition and the treatments required to manage it. None of AB's family suggest she would value her current quality of life.

56. On behalf of the Official Solicitor, Ms Paterson submits that the Official Solicitor has, with great sadness, concluded that it is no longer in AB's best interests to receive CANH and instead she should be provided with palliative care in accordance with the RHN's palliative care plan.

57. Ms Paterson submits the severity of AB's injuries was set out by Dr D in his written and oral evidence, which is supported by the evidence of Dr Nair.

58. Ms Paterson submits the evidence demonstrates that although the baseline level of AB's health has not changed significantly there is evidence of a decline as she requires more nursing interventions to remain stable, including increased suctioning, AB's limbs becoming increasingly stiff and difficulties in managing the monthly tracheostomy tube change.

59. Ms Paterson submits that the evidence is now overwhelmingly clear that it is no longer in AB's best interests to continue receiving CANH. AB's circumstances since 2015 would in all likelihood be unthinkable to her or at the very least distressing. It is now in her best interests to be afforded a peaceful, planned death through the implementation of the palliative care plan.

Discussion and decision

Actions of the RHN

60. The RHN is described as one of the largest centres in the United Kingdom for providing care, treatment and support to those with complex neuro-disabilities. It is an independent charity, although the majority of their patients are funded by the NHS. It believes that it has one of the largest, if not the largest, cohorts of patients in PDOC in the country. As Dr D observed, this is both a privilege and a significant responsibility.

61. Bearing in mind the size and expertise of the RHN it was all the more concerning that Hayden J was driven to make the observations that he did in *GU* about the delays in that case. There have been similar, if not longer, delays in this case. That has been as a result of a systemic failure within the RHN, unrelated to the high level of nursing care on the ground. The contents of Dr Luttrell's statement demonstrate the steps the RHN have taken since *GU* so they now have a system that is fit for purpose to make timely best interest decisions in these very difficult cases. A further statement from Dr Luttrell on 28 October 2024 provided a further update.

62. As Dr Luttrell set out in his first statement *'Whilst the RHN had relevant internal guidance and policies in place prior to this [GU] judgment, in recent years it has been working to develop and implement a more robust framework and system of support which ensures the best interest decisions in relation to CANH are made for our patients in PDOC in a timely*

manner. The RHN wishes to assure the court that it has fully engaged with the criticisms raised in the GU case and is fully committed to dealing with these. It has undertaken a significant review, with engagements from its Board…Ethics Committee and Executive Management Team who monitor progress and receive regular reports and is working to implement these changes fully'.

63. In that statement Dr Luttrell confirms that in 2018 the RHN's Board approved a policy which applied the then current national guidance on the withdrawal of CANH from patients with PDOC; *'This was applied in individual cases, but there was no system to proactively ensure that every patient in PDOC had a best interest decision that CANH should continue'.* Prior to the judgment in *GU 'the position at the RHN was that the provision of CANH continued unless concerns were raised about it for an individual patient. Whilst the RHN was engaged in best interest decision-making for a wide range of decisions for patients in PDOC, CANH and whether this should be continued or withdrawn was not a particular focus for the staff, unless this was raised by those close to the patient or there were specific clinical contraindications or a care plan which provided for discontinuance in specific circumstances. The RHN recognises that it had not given sufficient attention to proactive best interest decision-making in relation to CANH in patients in PDOC and whether continuing to receive this was in their best interests'.*

64. The RHN's Action Plan since the *GU* judgment has included

(1) The updating of the RHN policies so they now include a structured process for both existing and new patients. There are three key stages –

(i) a best interest decision (with consultation with those close to the patient by the decision-maker and the multi professional team);
(ii) a second opinion from an independent expert to confirm PDOC; and,
(iii) an assurance process that the requirements of the process have been met.

(2) A programme of training and education has been rolled out to staff, and

(3) Agreeing a protocol for how it can most productively work with the ICBs regarding timeframes and responsibilities for various actions to ensure applications are made to the Court of Protection in a timely way.

65. Once a decision has been made to discontinue CANH or if a decision needs to be referred to the Court of Protection as there is disagreement as to what is in the patient's best interests or it is finely balanced, the case will be discussed at the weekly Executive Management Team (EMT) meetings. If the EMT are satisfied the correct processes have been followed the matter is then referred to the RHN's Ethics Committee.

66. The RHN CANH Policy was ratified by the Board of Trustees in February 2022 and incorporates the recommendations of the Royal College of Physicians set out in *"Prolonged Disorders of Consciousness following sudden onset brain injury: National Clinical Guidelines, report of a working party (2020)"*; and *"Clinically-assisted nutrition and hydration (CANH) and adults who lack the capacity to consent, Guidance for decision-making in England and Wales (2018)".* In addition, there is a supplementary policy that deals with specific more complex scenarios, a number of process maps and templates that help support the RHN CANH Policy which set out the steps to be followed, who is responsible for completing each element and a range of further material which support the process of decision making, such as a guide for families.

67. Following the implementation of the RHN CANH Policy the RHN set up the CANH Implementation Group, which both Dr Luttrell and Dr D are members of. This group met fortnightly from its inception in March 2022 until January 2024 and now meets monthly, providing oversight and review to the implementation of the RHN CANH Policy.

68. To support this work the CANH Clinical Forum was set up to support the clinical teams making these decisions. It meets fortnightly to discuss cases and review the ongoing operation of the processes and systems that are in place which can be fed back to the CANH Implementation Group.

69. Dr Luttrell's statement sets out the extensive training that has taken place for clinical staff since September 2022, which include a Schwartz round (reflective practice forum) conducted in March 2023 with a focus on CANH decision-making.

70. The work with the ICBs who commission care at the RHN is continuing with the aim of agreeing a protocol which sets out the process for making an application to the Court of Protection in these cases, including timeframes and responsibilities for various actions.

71. As regards managing decision making for current patients as well as new patients Dr Luttrell reports that since October 2022 there have been 70 patients within the continuing care service at the RHN with a diagnosis of PDOC who are receiving CANH. Consultation in accordance with the RNH CANH Policy has completed for 51 patients. Decisions in relation to 7 patients have been referred to the ICB with a view to an application to the Court of Protection. The process is ongoing in respect of 17 patients (including those referred to the ICB) and 2 patientss have died before the best interest consultation process concluded. For patients newly admitted to the RHN, consultation and best interest decisions for any incoming patients in PDOC will commence within two weeks of admission.

72. The recent audit of those patients cared for in the RHN's BIS between September 2023 and August 2024 confirmed there were 38 patients who were in PDOC and receiving CANH. 22 patients had had best interest decisions made about whether they should continue to receive CANH, for the remaining 16 patients their clinical circumstances changed in various ways as described by Dr Luttrell.

73. This more structured process, with regular oversight and review, will mean that the unacceptable delay that occurred for AB, as it did in the *GU* case, will no longer occur and any applications that need to be made to the Court of Protection will be made in a structured and timely way.

AB

74. Turning to AB's situation. The delays that have taken place in making a best interest decision have been deeply concerning to the court for all the reasons outlined by Hayden J in *GU.*

75. There is no issue in this case regarding AB's lack of capacity to make any decision regarding her treatment due to the severity of her injury.

76. As long ago as 2015 AB was assessed as being in PDOC and the reviews undertaken since then has not changed that conclusion.

77. Proactive and effective best interest decision making regarding AB was only instigated in January 2023 after the decision in *GU* and the implementation of the RHN CANH Policy.

78. The medical evidence is striking in the clarity of its conclusions. Both Dr D and Dr Nair agree AB is in a MCS minus, with a number of pre-existing medical conditions. Her existence is one of total dependence requiring 24 hour nurse led care. Among her medical needs she has a long term sacral sore which she is being carefully treated for; she has a tracheostomy which requires suctioning every 3 – 4 hours, sometimes more frequently, and a PEG which requires daily care to prevent infection. There is some evidence to suggest that she may experience some pain although Dr D puts it no higher than a possibility due to the extent of her brain damage. However, the evidence points towards the logistics of being able to care for AB becoming increasingly difficult, for example the need for increased suctioning, the increasing

difficulty in managing the monthly change of her tracheostomy due to the tightening of her neck muscles and the increasing difficulty in managing her splint regimen.

79. As regards AB's wishes and feelings there is no evidence that AB has discussed or considered this situation prior to her injury. The only view she is said to have expressed to PB was that if she did become unwell he should not stop his life to look after her. As regards what her family and friends believe her wishes would be the majority feel her current situation is not something that she would have wanted.

80. It is against this background that the court is required to undertake a best interests analysis to decide what is in AB's best interests, in particular whether it is in AB's best interests to continue to receive CANH delivered through her PEG and, if not, whether it is in her best interests to receive palliative care only.

81. The medical evidence, which I accept, speaks with one voice that AB's PDOC is permanent with no prospect of any improvement.

82. The presumption of continuing life is an important and weighty consideration, continuation of CANH would do that and AB is a much loved family member and friend. These important factors must be carefully balanced with the other considerations. If AB remained in receipt of CANH it is expected that she could live for up to four years, subject to the risks arising from any supervening infection, such as a chest infection. If CANH was withdrawn it is expected that AB would die within seven to twenty one days, possibly less. She would be in receipt of the care and support outlined in the palliative care plan. The aim of the plan, in accordance with the RCP PDOC Guidance, is that AB should not suffer any distress which Dr D was able to explain in his oral evidence.

83. Against that important consideration there is a need to carefully consider and balance the burdens of AB's condition: AB has no communication, either verbal or non-verbal; limited awareness of herself or her surroundings; no purposeful movement save for involuntary movements of her head and left hand; orofacial dyskinesia (a type of involuntary movement with a typical pattern in the face and especially around the mouth); she is doubly incontinent; has thick secretions that require regular suctioning; suffers from frequent chest infections (required PEG antibiotics for pneumonias on nine occasions in 2023); frequently suffers from other infections (such as skin infections); has long standing sacral cleft skin issues; has had periods of autonomic instability; episodes of low blood pressure; hyper salivates which can cause difficulties with her skin and is wholly dependent on others for every aspect of her life and day to day care.

84. Within these considerations there are burdens arising from the treatment AB requires, such as injections for her spasticity, splinting regimen in her upper limbs that is becoming increasingly difficult to undertake, suctioning of secretions where AB displays behaviours associated with pain or discomfort when it is being done and increasing difficulty in the monthly changes of her tracheostomy. Whilst Dr Nair considers AB may experience pain. Dr D's view is that there is a possibility that AB has minimal awareness which could enable her to experience distress. Dr D said in his statement *'The nature of this distress is difficult to characterise in terms of its nature, intensity, and 'moment to moment' recall of that experience.'* As regards pleasure Dr D considered that the smiling that is reported is likely to be an involuntary movement without any meaning.

85. These amount to significant burdens to AB that arise both from her condition and from her treatment. Those burdens are, in my judgment, likely to get worse. I agree with the submissions of the Official Solicitor that AB now has little or no quality of life. Her life expectancy is inherently unpredictable, even with the high quality of care she is receiving and she is exposed to an increasing number of unpleasant, uncomfortable and undignified experiences through the level of nursing care that is required to keep her alive. AB's Article 2, 3 and 8 EHCR rights have been upheld by the RHN's adherence to the RCP PDOC

Guidelines and the external review by Dr Nair and Mr Mitchell. The Article 8 rights of AB's family have been protected through their full participation in these proceedings.

86. Considering the wide canvas of evidence, balancing the competing considerations outlined above I have, with deep sadness, reached the conclusion that AB's best interests in the widest sense require CANH to be withdrawn, as to continue to provide it is not in AB's best interests due to the very significant and increasing burdens her condition and treatment involves that outweigh the presumption of maintaining life.